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ABSTRACT

This paper describes a comprehensive approach to intervention and support for families of children experiencing traumatic brain injury (TBI) and behavior problems. It explains the need for child- and family-centered intervention approaches, discusses the theoretical basis and key features of one approach, summarizes the steps in the support process, and presents a case study of one family's efforts to support an 11-year-old boy with TBI and severe behavior problems. Five key features characterize the recommended approach: a theory-guided understanding of child behavior problems and family ecology; design of multicomponent, positive behavioral support plans; ensuring a "goodness-of-fit" between the support plan and family ecology; focus on building successful family routines; and development of collaborative partnerships. The seven-step behavioral consultation process recommended includes: (1) referral; (2) comprehensive assessment; (3) preliminary plan design; (4) team meetings and plan finalization; (5) implementation support; (6) continuous evaluation and plan revision; and (7) follow-up support. The entire process is illustrated in the case study in which clinically significant improvements in child behavior were achieved and maintained during follow-up measures 3 and 4 months after intervention. (Contains 56 references.) (DB)

Running Head: Family Support

Comprehensive Family Support for Behavioral Change in Children with Traumatic Brain Injury

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Comprehensive Family Support for Behavioral Change in Children with Traumatic Brain Injury

This chapter describes a comprehensive approach to intervention and support with families of children experiencing traumatic brain injury and behavior problems. The goals of the approach are to improve the behavior and lifestyle of the child with traumatic brain injury, to empower family members to effectively reintegrate the child into family life, and to help the family regain the cohesion and stability that are often shaken or lost after such an injury to a family member. The chapter describes the need for child and family-centered intervention approaches, discusses the theoretical basis and key features of one particular approach, summarizes the steps in the support process, and presents a case study of one family's effort to support an 11-year old boy experiencing traumatic brain injury and severe behavior problems.

The Need For Child And Family Centered Approaches

A traumatic brain injury to a child traumatizes the whole family (Pieper & Singer, 1991; Williams & Kay, 1991). In one survey, 80% of the parents of children with traumatic brain injury (TBI) reported symptoms that met the DSM-IIIR criteria for Post-Traumatic Stress Disorder which is a disorder experienced by war veterans and survivors of catastrophic events (Nixon, 1992). Just as children who have survived TBI experience lifelong alterations, the families of these children also experience changes in the pattern of their daily lives, in their roles and care giving responsibilities, and in their expectations and hopes for the future. Children often experience deficits in cognitive abilities such as memory, organizing, planning, decision-making and problem-solving. Children who were formerly well behaved, well-liked by peers,

and successful in school may engage in behaviors that disrupt family life, friendships, and schooling. The confusion, grief, and disruption associated with these changes can overwhelm families. Family members may have difficulty maintaining or recreating the structure, order, and predictability that characterized their lives together before the injury. As they proceed through the rehabilitation process, both children with TBI and their families experience the falling away of family and friends and the dwindling of their social support (Livingston, Brooks, & Bond, 1985; Williams & Kay, 1991). This loss of social support may make the family's effort to regain stability and hope even more arduous. Clearly, the effects of the child's brain injury ripple through the structure and experience of the family.

The child's and the family's experience both parallel and interact with one another. For example, many children with TBI have behavior problems such as inappropriate social behaviors, aggression, and destructive tantrums. Such problems may begin as child-centered difficulties directly related to the brain injury, but the problem behaviors then come to affect the family system. The family's reactions to the child's behavior can affect whether these behaviors are maintained or changed (Dadds, 1995; Florian & Katz, 1991; Patterson, 1982). If a child's behavior is going to change, both the child and the family must change. Effective interventions therefore must be both child-centered and family-centered. This notion that the rehabilitation of the child and the family are inseparable is becoming more predominant in the special education field (Turnbull & Turnbull, 1991a) and in the TBI rehabilitation field (McKinlay & Hickox, 1988).

Despite these conceptual developments, there remains very little intervention research with families of children with TBI. Although behavioral intervention in residential rehabilitation facilities has been shown to effectively reduce behavior problems and rebuild adaptive skills among adults with TBI (Burke, Wesolowski, & Lane, 1988; Davis, Turner, Rolider, & Cartwright, 1994; Peters, Gluck, & McCormick, 1992), to date, no comprehensive intervention approach has been developed and shown to be effective with children with TBI and their families. In the family intervention literature, a family network strategy has been anecdotally reported to be helpful to families of children with TBI, but no data were gathered (Rogers, 1984). The family systems approach has been discussed in terms of its application to families and children with TBI (Turnbull & Turnbull, 1991a), but as yet there have been no attempts to empirically validate this approach with families of children with TBI. A definite need thus exists for the development and evaluation of comprehensive approaches to intervention aimed at addressing the challenges faced by children with TBI and their families.

Theoretical Basis And Key Features Of Approach

The comprehensive approach to intervention with families of children with TBI adopted here is drawn from current best practice in behavioral support to persons with disabilities and behavior problems (Carr, et al., 1994; Horner, et al., 1990; Meyer & Evans, 1989; Wacker & Steege, 1993), behavioral parent training (O'Dell, 1985; Patterson, Reid, & Dishion, 1992; Sanders & Dadds, 1993) and ecological approaches to family assessment and support (Bernheimer, Gallimore, & Weisner, 1990; Singer & Powers, 1993). Five key features characterize the approach: (a) a theory-guided understanding of child behavior problems and

family ecology; (b) the design of multicomponent, positive behavioral support plans; (c) a "goodness-of-fit" between the support plan and family ecology; (d) a focus on building successful family routines; and (e) the development of collaborative partnerships. These features are each discussed below.

Theory-guided Understanding of Child Behavior and Family Ecology. A central message in the literature on behavioral assessment and intervention is the importance of understanding the reasons for behavior problems, and the ecology in which behavioral support will be implemented. This information is essential for the design of effective, acceptable, and feasible behavioral interventions (Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991; Horner, 1994). Applied behavior analysis research and social learning theory (Patterson, 1982; Wacker, Cooper, Peck, Derby, & Berg, in press) indicate that child behavior problems serve a clear purpose or function, and that behavior problems are developed and maintained within the moment-by-moment interactions between the child and parent. For example, a child with TBI who has become impulsive may demand that his mother bake cookies for him just before bedtime. If his mother refuses and her son whines and hits her, she may relent and bake the cookies. The child might then stop his aggression, and even help with baking. Although the mother may initially submit out of a sense of compassion for a son who has experienced so much trauma, her response also teaches an unintended lesson. That is, the child learns that aggression is an effective way to get what he wants when he wants it. The mother also learns something dysfunctional; that giving in to her son's unreasonable demands avoids or terminates aggressive behavior. These coercive processes, once embedded in family interaction patterns, may be difficult to change without

systematic intervention (Patterson, et al., 1992). Via functional assessment of the child's behavior problems, the purposes of the child's behavior can be understood, and the consequences that maintain behavior problems and ineffective parenting strategies can be revealed. This knowledge then informs the design of child-centered interventions that will render behavior problems ineffective at achieving their purposes, and that will rebuild family members' ability to effectively parent the child.

Ecocultural theory (Gallimore, Weisner, Bernheimer, Guthrie, and Nihara, 1993; Gallimore, Goldenberg, & Weisner, 1992) is a theory of child development in the family derived from cross-cultural ethnographic studies of family life (Whiting & Edwards, 1988). It provides a useful framework for understanding ecological influences on child development in the home and for designing interventions that are individualized to the family. The theory supposes that families socially construct child activity settings (i.e., daily routines) to accommodate the needs of their children within the constraints and opportunities present in the family's environment. Gallimore and colleagues (see also Bernheimer, et al., 1990) argue that daily routines are the appropriate unit of analysis for understanding the ecology of a family and for designing family-centered interventions because ecological influences on the family are present and can be observed to operate in each family routine. According to ecocultural theory, daily routines comprise several elements: (1) time and place; (2) persons present; (3) material resources; (4) goals, values, and beliefs about child raising and family life; (5) tasks and how they are organized; (6) motives and feelings; and (7) common scripts or patterns of interaction. Families proactively strive to construct routines that are meaningful given their values, congruent with their children's

characteristics, and sustainable over time. The construct and concurrent validities of ecocultural theory were recently demonstrated by Nihira, Weisner, and Bernheimer (1994) in a longitudinal study of 102 families of children with developmental delays.

During assessment with families of children with TBI, an analysis of daily routines is particularly useful. When families discuss their efforts to parent their child with TBI, it is not uncommon for them to describe their successes or difficulties in rousing the child for school in the morning, orchestrating a pleasant dinner together, or helping the child prepare for bed. For many families of children with TBI, routines that once worked reasonably smoothly are now fraught with obstacles and problems, not the least of which are behavior problems. As the family describes the elements (e.g., goals, tasks, resources) of routines, many layers of the family's ecology are revealed, including family values, structure, functions, and interaction patterns. Viewing the daily routine as a microcosm of family ecology can lead in several ways to the design of individualized and effective family interventions. First, it suggests that interventionists should view the unit of analysis and intervention as the family routine, as opposed to focusing solely on behavior problems and parenting skills. Second, it encourages interventionists to design child- and family-centered interventions that are effectively embedded in family routines. Lastly, if interventions support the success of valued routines, they are more likely to be accepted and implemented by the family.

Design of Multicomponent Positive Behavior Support Plans. The technology of positive behavioral support, that has emerged largely from work with persons with severe disabilities, has much to offer children and families experiencing TBI. The approach emphasizes the design of

individualized, multicomponent behavioral support plans. These plans are logically linked to functional assessment data, and serve not only to ameliorate behavior problems but also to promote lifestyle improvement (Horner, et al., 1990). Interventions are drawn from a growing body of empirically verified ecological/lifestyle, antecedent/proactive, educative, and consequent interventions, with an emphasis on prevention and education. Support plans are designed collaboratively with family members, educators, and other consumers of the support plan, and only those interventions judged to be acceptable and likely to be effective are included in the plan (Sprague & Horner, 1991). Positive behavioral interventions verified through applied research include improving activity patterns (Malette, et al., 1992), offering choices (Dunlap, et al., 1994), providing information to increase predictability (Flannery & Horner, 1994), teaching communication skills to replace behavior problems (Carr, et al., 1994), teaching self-management skills (Kern Koegel, Koegel, Hurley, & Frea, 1992), and embedding preferred tasks within non-preferred tasks (Horner, Day, Sprague, O'Brien, & Tuesday Heathfield, 1991).

Two critical features of positive behavioral support, a focus on life style change and the importance of multicomponent intervention plans are particularly relevant to the needs of children with TBI. Children with TBI often experience dramatic setbacks in their lifestyle. A child may no longer be able to participate in favorite activities requiring abilities that have been compromised due to the injury (e.g., sports). Friendships may be lost and difficult to reestablish. Conversation with family members may be harder to start or maintain. This loss of valued experiences can alone be a source of behavior problems. Lifestyle interventions that emphasize

the rebuilding of valued activities and social relationships may help to ameliorate behavior problems.

Children with TBI also experience behavior problems for a variety of reasons that are unlikely to be adequately addressed by only one or two behavioral interventions. In addition to lifestyle deficits, children with TBI may experience impairments of bodily function, loss of impulse control and social skills, frustration with communication and academic performance, and interactions that may inadvertently reinforce behavior problems. Also, for any particular child with TBI, behavior problems may serve different purposes such as attention-getting, avoidance of aversive tasks, or protestation of a lost ability or opportunity. A comprehensive behavior support plan must address all of the relevant conditions that trigger or maintain behavior problems, and each of the purposes of the child's behavior (Horner, O'Neill, & Flannery, 1993). For example, a child with TBI may cry and scream uncontrollably whenever she sees other children playing sports activities. This event may painfully remind her that since her injury, she no longer participates in swim meets or gymnastics. She may also scream when her father talks with her brother but does not include her in the conversation. Though the behavior problems are the same in each example, the purposes of the behavior are quite different. In the former, the child screams to protest a lost opportunity; in the latter, she screams to get attention. Interventions need to address each separate purpose directly if the family hopes to reduce screaming. Potential interventions logically linked to the functions of screaming might include creating opportunities to participate in sport activities geared toward her more limited abilities, and teaching her to ask for attention and participate in conversation. Because behavior problems

often serve multiple purposes, support plans will necessarily require multicomponent interventions.

"Goodness-of-Fit" with Family Ecology. The effectiveness of a well designed positive behavioral support plan depends on the extent to which interventions are in fact carried out. Effectiveness can also be judged by the degree to which interventions are implemented and maintained across all of the relevant settings in which behavior problems occur. Recently, behavior analysts and family interventionists have suggested that behavioral support plans are more likely to be implemented with fidelity and maintain over time if they fit well with the ecology of the family (Albin, Lucyshyn, Horner & Flannery, in press). Family variables relevant to "goodness-of-fit" include family goals, strengths, available formal and informal resources, and sources of stress. Behavioral interventions that fail to address family goals, that ignore family strengths, or that add significant stress will not be implemented or sustained. For example, a parent may desire to eliminate behavior problems and to receive more help from other family members. If the support plan includes interventions aimed only at reducing behavior problems but provides no means to strengthen informal supports in the home, the plan may fail due to parental exhaustion or resentment. Interventionists need to listen to families and learn about their goals, strengths, resources, and stressors. They then need to collaborate with families and other stakeholders in the child's life (e.g., teacher, physical therapist) to design interventions that are not only technically accurate but also contextually appropriate and feasible (Horner, 1994).

Building Successful Family Routines. A common subjective experience of families of children with TBI is to feel overwhelmed by the changes in their child and in their family's life.

A multicomponent support plan should be designed to ameliorate, not add to, these feelings of helplessness. One strategy to make comprehensive support feel "doable" to the family is to implement interventions in one routine at a time. Doing so may make the plan appear more feasible, and thus strengthen the family's perception that the plan will work. Intervening on the level of the routine may help the family cognitively reframe the challenges they face in supporting their child's rehabilitation (Turnbull, et al., 1993). Rather than facing an insurmountable crisis, the family may see that they face the more manageable task of improving routines that are no longer working.

Another benefit of tailoring interventions to fit family routines relates to the family's interpretation of a stressor such as a pediatric head injury. The impact of a stressor is mediated by an individual's interpretation of it (Lazarus & Folkman, 1984). Therefore, the impact of a child's brain injury on the family is affected by the perception of stress by the family (Chwalisz, 1992). One family may find the personality change of their child to be the greatest stressor, while another family may experience the loss of social support as the most stressful outcome. The brain injury to a child should be understood in terms of the subjective experience of the family, and interventions should be tailored to that subjective experience. For example, interventions designed to improve a bedtime routine in which one parent is stressed by exhaustion and feelings of isolation are likely to include skilled respite care at other times of the day, and a weekly schedule of help during the routine negotiated with other family members.

The importance of routines to family coping is supported by research on everyday stressors and hassles (Kanner, Coyne, Schaeffer, & Lazarus, 1981). Some researchers have found daily

hassles (e.g. disruptions in daily routines) to be a better predictor of family stress and coping than major life events (Delongis, Coyne, Dakof, and Folkman, 1982). The implication of this finding for interventions with children with TBI and their families is clear: The impact of the brain injury on a family is, to an extent, mediated by disruptions in daily routines. It follows then that the negative effect of the brain injury on the child and the family can be ameliorated by making family routines more effective and `hassle-free'.

A final advantage in intervening at the level of the routine is that generalization and maintenance of treatment effects may be more likely because behavioral interventions are embedded within the ecology of routines (e.g., goals and values, tasks, resources) (Albin, et al, in press; O'Donnell & Tharp, 1990). Families who succeed in promoting behavioral change in two or three routines may find it easier to apply interventions in other routines that share similar properties. For instance, if a mother successfully motivates her son to go to bed cooperatively by reviewing behavioral expectations and negotiating a reward natural to the routine (e.g., reading a story to him after completing the routine) she may use similar practices to motivate him to behave properly at the dinner table. Also, behavioral improvement may endure over a long period of time because the interventions were specifically tailored to fit the ecology of the routine, including the social supports necessary for maintenance. For instance, if both parents equally shared the task of supporting their son in the bedtime routine, both parents may get the rest they need to continue using the support plan.

Building Collaborative Partnerships. The values and practices in the family support approach are designed to empower family members and to build strong collaborative relationships between

the consultant, the family, and the other team members (Dunst, Trivette, Gordon, & Starnes, 1993). Family knowledge is respected and collaboration with the consultant and other team members is encouraged throughout assessment and intervention. Families of children with TBI are the ultimate experts on their child's strengths and behavior problems, and on their family's ecology. Although the family may feel overwhelmed as a result of the trauma to their child and the disruption to their lives, they still possess many strengths and resources that can contribute to the success of a support plan.

It is therefore essential that family members collaborate in the design and selection of behavioral interventions, in the selection of routines in which to intervene, and in the choice of implementation support activities. Family members also should evaluate the acceptability and effectiveness of plan goals, interventions, and outcomes, and recommend revisions in interventions or support activities that are not working well. The consultant should encourage collaborative relationships between the family and key stakeholders such as the child's teacher or skilled respite care providers via team meetings, coordination of implementation across home and school, and development of formal supports to the family (e.g., skilled respite care). These values and practices contribute to the development of a strong therapeutic alliance between the family and the consultant (Kanfer & Grimm, 1980) and to the development of a community of support around the child and the family. Such an alliance and community can help to overcome the trauma of TBI and help to rebuild the child's and the family's life together.

Steps in the Comprehensive Family Support Process

The key features of the support approach have been organized into a seven step behavioral consultation process: (1) referral, (2) comprehensive assessment, (3) preliminary plan design, (4) team meetings and plan finalization, (5) implementation support, (6) continuous evaluation and plan revision, and (7) follow-up support. The process, described in detail by Lucyshyn and Albin (1993) is briefly summarized below with emphasis on the way in which each step in the process is relevant to children with TBI and their families.

Referral. The referral interview has several purposes. First, during the initial interview, the consultant assesses for extreme situations such as life-threatening behavior or suicidal tendencies. These kinds of situations require immediate action by the consultant. During the referral interview the consultant also obtains informed consent. The consultant informs family members of what will be involved in the development and implementation of a comprehensive family support plan, emphasizing that the plan will be developed cooperatively with the family.

Another purpose of the referral interview is to identify the stakeholders whose participation could contribute to improvement in the child's behavior and lifestyle. In addition to the child's parent(s), stakeholders may include siblings, friends, education professionals, and community service representatives (e.g., scouting, respite services). Potential stakeholders nominated by the family are invited to participate in assessment and plan design activities as members of a family support team.

The referral interview provides an occasion to reframe the family's problems in a more positive light. The consultant stresses that as the child's family, they possess most of the information needed to design a support plan, that the support effort will be guided by their values, and that the plan will build on their strengths. The consultant also notes that intervention will occur in the context of family routines, and that the family will participate in the selection of routines, interventions, and support activities. Finally, the consultant also shares with the family success stories about prior interventions with other families similar to themselves. The goal of the reframing process is to help the parents believe that they are powerful, in control, and capable of effecting change.

Comprehensive Assessment. The synthesis of child and family-centered approaches to intervention is reflected in the second step of the support process. The assessment consists of a functional assessment of behavior problems and a family ecology assessment. The goal of the functional assessment is to provide information necessary for the design of an individualized behavioral support plan for the child. The goals of the family ecology assessment are to provide information necessary for the design of family-centered interventions, and for the creation of a "goodness-of-fit" between the behavioral support plan and the family's ecology.

The functional assessment uses the assessment protocol designed by O'Neill and associates (O'Neill, Horner, Albin, Storey, & Sprague, 1990). Information gathered during the assessment includes: (1) a specific description of behavior problems; (2) ecological factors associated with those problems (e.g., medical problems, activity patterns); (3) educational factors (e.g., skill

deficits in language); (4) common predictors (e.g., interruptions, difficult tasks, transitions); and (5) possible functions of the behaviors and their maintaining contingencies.

Assessment activities consist of interviews and observations in home, school, and other relevant settings as appropriate. In addition to family participants, interviews and observations typically include other team members such as the child's teacher or physical therapist. Interviews are casual, jargon-free, and respectful of the knowledge and expertise of each team member. The consultant also may ask parents or teachers to complete observations in the home or school using a functional analysis observation form (O'Neill, et al., 1990). From these interviews and observations, the consultant develops hypotheses about the functions of behavior problems and about the promotion of desirable behavior.

The family ecology assessment consists of two interviews. During the first interview, the family replies to open-ended questions about family goals, strengths, resources and social supports, and sources of stress (Turnbull & Turnbull, 1991b; Summers, Behr, & Turnbull, 1989). During a second interview the family describes the daily routines in which their child participates. After enumerating all current routines, the family identifies 3 or 4 routines in which they would like to intervene, and then describes what each routine would look like if it were successful.

In addition to gaining information necessary for the design of a comprehensive family support plan, the assessment process gives the family critical information about their child and family. When families conduct functional analysis observations, they discover the types of interactions or events that trigger behavior problems, and the purposes that the child's behaviors

serve. Behavior problems become cognitively reframed from willful acts of noncompliance to inappropriate attempts to satisfy important wants and needs. The family ecology assessment has a similar awareness-building function. For instance, when families talk about their strengths, they are reminded that despite the trauma of TBI, they still possess many qualities of an effective family: Both parents may recognize that they remain loving and forgiving in their relationship with their children; a mother may see that her ability to coordinate family activities remains intact; a father may realize that he continues to effectively support his children. Acknowledging strengths and resources helps families regain the sense of hope that may have been lost through grief and the struggle to cope.

Preliminary Plan Design. During and immediately after the comprehensive assessment the consultant engages the family and other team members in a dialogue about the content of a preliminary positive behavior support plan and implementation plan. Guided by the hypotheses generated during the functional assessment, they together discuss interventions that may render behavior problems irrelevant, ineffective, and inefficient in achieving their purpose. Five categories of intervention are considered: (1) ecological/lifestyle interventions; (2) antecedent/proactive interventions; (3) interventions to teach new behaviors or skills; (4) effective consequences; and (5) emergency procedures. Effective consequences typically include positive reinforcement strategies to strengthen adaptive behavior and de-escalation procedures to weaken behavior problems. Emergency procedures may be proposed if necessary to prevent physical injury or property destruction.

Information from the family ecology assessment is used to select child-centered and family-centered interventions that advance family goals, build on family strengths, use resources and social supports available to the family, and diminish sources of stress. For example, family goals may include helping their child with TBI make new friends, and finding ways for the parents to get more rest from care giving responsibilities. Interventions may include enrolling the child in the local chapter of Girl Scouts or developing a small group of skilled respite care providers. Information about family routines helps with the design of child-and family-centered interventions that are effectively embedded in the routines. For example, during a dinner routine an older sibling with an affectionate relationship with her brother with TBI may be willing to praise her brother for appropriate behavior during the meal.

The family and the consultant also discuss potential implementation support activities. The family and consultant collaboratively decide on the routines in which to intervene, and on the activities that will support implementation and long term maintenance. Potential activities include home meetings, behavioral rehearsal, and coaching in the actual routine. The result of this dialogue is a preliminary implementation plan that includes recommendations for support activities, roles, and timeline.

Team Meetings and Plan Finalization. The purposes of the team meeting are to finalize the behavioral support plan and implementation plan and to build collaborative relationships among team members. In preparation for the team meeting, the consultant summarizes functional assessment data and preliminary plans on flip charts. During the meeting, the consultant highlights the results of the assessment, reviews hypotheses, and guides a discussion of potential

behavioral interventions and implementation activities. During the review and discussion team member input is solicited. Plans are presented tentatively, and team members are encouraged to change, add, or delete any part(s). When disagreements arise, they are negotiated until there is consensus.

Effective team meetings achieve consensus on every level. Consensus about hypotheses, goals, interventions, and implementation activities will allow the finalized plans to be supported by all team members. Consensus also may strengthen collaborative relationships and commitment to improving the behavior and lifestyle of the child and family. Finally, consensus creates a context in which the family can be supported in the implementation of interventions, and in which responsibilities can be delegated and accomplishments acknowledged.

Implementation Support. During the implementation phase the family, the consultant, and other key stakeholders implement the behavioral support plan. Support activities defined in the implementation plan, such as behavioral rehearsal and home meetings are used to: (1) build or strengthen the family's capacity to support the child, (2) help enact lifestyle changes, and (3) sustain collaborative relationships. Most support activities take place in the family's home or neighborhood because this is where child and family problems occur. Changes in the behavior of a child with TBI can be made at a residential or rehabilitation facility, but these changes are unlikely to maintain when the child returns home if the reinforcement and interactional patterns of the family as a whole have not been changed (Willer & Corrigan, 1994).

When implementation begins, the consultant initiates support activities tentatively and flexibly. Some families may like a particular support activity (e.g., role play) while other

families find the same activity stressful. Thus, support activities need to be undertaken with flexibility until the right mix of effective and acceptable activities for a family is discovered.

Support activities commonly used during implementation support include: (1) written procedures that succinctly describe interventions and provide examples and non-examples of appropriate use; (2) implementation checklists that parents use to self-evaluate and self-monitor implementation fidelity; (3) behavioral rehearsal (role-play) in which parents and the consultant practice how to implement interventions; (4) coaching in the natural performance setting, involving instruction, modeling, and feedback; (5) home meetings where progress is reviewed, accomplishments acknowledged, and new or recurring problems solved; and (6) telephone consultation.

Continuous Evaluation and Plan Revision. Multiple methods of evaluation are used to assess the outcomes of the comprehensive family support effort. These methods are designed to answer four central questions: (1) Has the plan promoted meaningful and durable behavior change for the child; (2) has the plan improved the lifestyle of the child and family; (3) do parents and stakeholders use interventions effectively; and (4) do family members perceive plan goals, interventions, and outcomes as acceptable and effective?

Potential evaluation methods include direct observation, implementation checklists, social validity questionnaires, and qualitative interviews with key informants (e.g., parents, siblings, teacher). Methods of evaluation are selected during the team meeting and used continuously during implementation support. Information gained from evaluation data guide changes in implementation support activities, and revisions in child-centered and family-centered

interventions. When the data from multiple methods converge to indicate that the central aims of the support effort are being achieved, the consultant begins to fade his or her support, and the family and consultant confirm a date to terminate the consultant's regular participation in support activities.

Follow-up Support. Although interventions may prove effective and the support effort evaluated a success, the endurance of these positive changes cannot be assumed. For the child to continue his or her progress, the family will need to continue implementing interventions with fidelity, solve new problems as they arise, and respond deftly to life-cycle developments in the child and family. A variety of stressors are likely to impinge on the family, and may hinder family members' ongoing ability to support their child. Although behavior problems may have been reduced to near zero levels, they rarely disappear. The potential for regression is thus ever-present.

For these reasons, families often need follow-up support. At the conclusion of implementation support, families are encouraged to call the consultant when problems re-emerge or new issues arise. Sometimes these problems can be resolved through a series of phone consultations. Other times a home meeting may be required. In some cases where skills have eroded or interventions have been neglected, a series of coaching sessions in the home may be necessary.

Case Study

Michael was 11 years old at the time of the study. He lived at home with his mother and father, Peggy and Alan, and four siblings: Two older sisters, 14 and 17 years of age; and 2

younger brothers, 5 and 8. The family lived in a four bedroom house in a middle class neighborhood in a pacific northwest community of approximately 100,000. Both parents worked outside of the home.

Michael was 8 years old when he ran across a street and was hit by a car. In the accident, Michael suffered a severe brain injury with brainstem contusion and was comatose for approximately 4 months. Michael's initial hospitalization was agonizing for his family because they did not know if he would come out of the coma, or whether he would live or die. His parents described the experience as "unreal." They believed that when he awoke, Michael would be himself again. They reported that after he awoke and they realized his loss of ability, they experienced a shock from which they had not yet recovered.

After 4 months, Michael was transferred to a rehabilitation unit where he remained for 3 months before coming home. During those 7 months in the hospital, Peggy devoted almost all of her time to Michael at the hospital and was not available for the other four children. Only one of the siblings, his 14 year old sister, visited him at the hospital.

Outpatient rehabilitation occurred for two months, and then the family moved to another state where rehabilitation continued. The parents reported that immediately following the accident the family received much social support from their friends at church, but the subsequent move separated them from their social support network. The family had difficulty building a new social network in their new community, and at the time of the study Michael didn't have any friends.

Prior to the accident Michael had been in a talented and gifted educational program, performing at a grade and a half above his age level. Neuropsychological testing approximately one year post-injury revealed a significant visual-spatial deficit, poor fine motor control, and slow and dysarthric speech. He scored in the low-average range on a measure of intelligence and two to three grade levels below his expected grade level on academic measures. As a result of this loss of ability, Michael was placed in a self-contained special education classroom in his neighborhood school.

Michael's parents reported that before the accident he was a star athlete and soccer player. At the time of the study, the right side of his body was weak, the right side of his face drooped, and his right hand shook. Because of the weakness in his right leg, he walked with a limp, was very unsteady, and often fell down. He used his left hand to feed and dress himself. He wasn't able to write with his left hand and so wrote using a computer and keyboard.

Michael's personality and behavior also changed after the accident. He developed a temper that was much more difficult for him or others to control. He screamed, hit, bit, and threw things in flashes of intense anger not in that degree before the accident. Once he escalated into high intensity behavior problems, it was difficult for him to regain his composure. Like many children with TBI, he also lost many of his social skills. He asked strangers inappropriate questions, said whatever popped into his mind no matter how inappropriate, and acted immaturely in interactions with his peers.

Referral

At the time of referral, Michael's family was desperate about their inability to control his angry outbursts and destructive behavior. They had seriously considered placing Michael in an inpatient program for children with TBI at a cost of $20,000 per month. Michael's mother had participated in several support programs (stress and behavior management classes, a parent support group) for families of children with TBI, but her participation was episodic, and the services were not intensive enough to overcome Michael's behavior problems and related family problems.

Peggy learned about the availability of the comprehensive family support process during individual counseling at a counseling center that served families of children with disabilities. During the referral interview the family counselor described the comprehensive family support process, and emphasized the home-based and collaborative features of the approach. Peggy expressed a strong interest in participating while her husband Alan, though skeptical about the chances for success, was willing to try. The family consented to participate for a nominal fee, and also agreed to take part in research activities to evaluate child and family outcomes.

Comprehensive Assessment

Functional Assessment. The consultant completed functional assessment activities with Michael's parents, his elementary school teacher, his sisters, and a volunteer respite care provider who had established a positive relationship with Michael. Assessment activities included functional analysis interviews, functional analysis observations in the home and school, and discussions about the purposes of behavior problems and about interventions that might

strengthen desirable behavior or diminish behavior problems. Assessment activities were completed across a 5 week period and required approximately 15 hours.

The functional assessment indicated that Michael primarily engaged in behavior problems in the home or community in the presence of family members. At school, Michael was in a highly structured program that included many functional and preferred activities, and the teacher was highly skilled in curriculum design and behavior management. Michael engaged in three types of behavior problems: (1) aggressive behaviors including slapping, hitting, kicking, and throwing things; (2) property destruction such as knocking objects off tables, and ripping clothing and furniture; and (3) whining and screaming. These behaviors sometimes occurred in an escalating sequence beginning with whining and screaming and ending with aggression or property destruction.

In the home several ecological conditions appeared to set the stage for behavior problems. Michael spent much time with his mother after school, and had few opportunities to leave the house and visit friends or engage in favorite sport activities. His mother often felt exhausted from her job, taking care of a large family, and being the primary care provider for Michael. Michael's father sometimes engaged in rough house play with the boys, including Michael, which involved playful slapping and punching. Siblings often avoided him because of fear of being slapped or hit. Several features of home routines appeared to provoke behavior problems including competition among brothers at the dinner time, difficult tasks during homework, unstructured leisure time in the middle evening, and an early bedtime next to a noisy family room.

Many of Michael's skill deficits were associated with his behavior problems. He had difficulty remembering social rules and controlling feelings of embarrassment, frustration or anger. His memory and communication deficits made it harder for him to ask for help or negotiate compromises. He also had difficulty structuring free time and remembering scheduled events. Finally his loss of motor skills seriously limited his opportunities to participate in previously enjoyed sport activities.

Several types of interactions and events appeared to contribute to and maintain his behavior problems. These included task demands, adults failing to fulfill promises, delays in having requests fulfilled, and seeing peers engaged in sports that he could no longer do. A typical pattern was for Michael to make a request for an item or activity followed by his mother saying "no" or asking him to wait until another time or day. Michael would then escalate into behavior problems ranging from low (whine) to high (hit) intensity until his mother gave in to his demands. Peggy, through this form of coercive training by the child (Patterson, 1982), began to fulfill unreasonable demands at earlier stages in the escalating sequence of interactions. Another common pattern occurred when Michael refused to engage in tasks he didn't like, such as getting ready for bed. He would whine, scream, or hit a parent until the parent withdrew the task demand, delayed the non-preferred event (e.g. going to bed), or escalated into shouts, physical prompts, or corporal punishment.

Four hypotheses about the functions of Michael's behavior problems emerged from the assessment: (1) Michael whined, screamed, or hit to get attention or assistance; (2) Michael whined, screamed, aggressed, or engaged in destructive behavior to get an item or activity; (3)

Michael whined, screamed, aggressed, or destroyed to avoid a non-preferred task, activity, or person; and (4) Michael aggressed and destroyed to protest a loss of ability or opportunity. These hypotheses served as the foundation for the design of a multicomponent positive behavioral support plan that addressed each purpose of Michael's problem behavior.

Family Ecology Assessment. Peggy was the primary participant in the interviews about the family's ecology, with Alan confirming information and describing his own experiences and perspective. Interviews about family characteristics and routines were completed across 4 meetings in the home. In the first 2 meetings, Peggy and Alan described their goals, strengths, resources and social supports, and stressors. During subsequent meetings, Michael's parents identified 4 family routines they wanted to improve, described the current structure of each routine, and generated a vision of what the routines would look like if they were successful.

The family assessment revealed that despite the presence of many stressors, the family had clear goals, possessed many strengths, and benefitted from several resources and social supports. For example, the family wanted Michael to learn to manage his own personal needs and free time, and to better tolerate errors, mistakes, and disappointments. His mother wanted other family members to share child care and household chores more equitably. The family had strong Christian values that encouraged family members to continue caring for each other despite the many difficulties they faced. On his own, Michael's father naturally used several effective strategies (e.g., telling Michael what to expect, offering calm reassurance) to help his son remain calm and cooperative. Informal resources used by the mother included help with child care and household chores from her husband and daughters. Effective formal resources included

Michael's teacher, who maintained excellent communication with Peggy. The family also received money from an insurance settlement that helped defray the costs that had been incurred since Michael's accident.

These positive characteristics provided a counterbalance to the stressors felt by family members: Michael's behavior problems, Peggy's exhaustion and frustration with the unequal distribution of child care tasks in the home, and Alan's sense of powerlessness in the family. Prior to the interview, Peggy and Alan thought their family had become totally dysfunctional; afterwards, they began to reframe their concept of their family as a healthy one struggling to overcome challenging yet definable obstacles.

During the discussion of family routines, Peggy and Alan decided to promote change in four routines that were not working well: (1) an early evening dinner routine in which family members sat together and ate in the dining room; (2) a homework routine in which Michael's parents helped him complete homework; (3) a middle evening leisure routine in which Michael attempted to entertain himself and interact with other family members; and (4) the bedtime routine in which Michael's parents helped Michael get ready for bed. Peggy first described each routine in terms of the elements of activity settings (e.g., goals, tasks, resources; O'Donnell & Tharp, 1990). Following her description, she then envisioned what each routine would look like if it were successful. During this exercise, the consultant encouraged Peggy to reconstruct the routine in her mind so that it was: (1) consistent with Michael's strengths and limitations, (2) congruent with family goals and values, and (3) sustainable over a long period of time. A description of the family's current and envisioned bedtime routine illustrates the process.

Peggy usually started the bedtime routine for Michael earlier than his two younger brothers (around 8:00 p.m.). Michael's bedroom was adjoined to his parent's bedroom and the living room where his younger brothers continued to watch T.V. or play together. The main resource to Peggy during the routine was Alan, who usually took over the routine when Michael began to "hassle" his mother. Meanwhile, her daughters were usually upstairs watching T.V. or in the dining room talking or snacking. They typically did not offer to help. The tasks in the routine were for Michael (with prompting from a parent) to go to his room, get his pajamas on, use the toilet if needed, brush his teeth and wash his face, and go to bed. Once in bed, Michael's father sometimes read him a story. Peggy's goals and values included: (1) Michael going to bed early; (2) the children going to bed clean, peaceful, and happy; and (3) Michael staying in his bedroom. Motives and feelings included Peggy worrying about how Michael would behave, wanting to get Michael "out of the way" so that she could get some rest, feelings of exhaustion, and resentment at the lack of help from other family members. Patterns of interaction during the routine were predominately negative: `parent demands followed by child whining and aggression; and Peggy asking Alan for help after behavior problems escalated.

Having gained some insight into the family's current bedtime experience, the mother and consultant discussed what a successful routine would look like. Peggy envisioned a routine in which most elements were changed or expanded. Alan would help more proactively and more often. Her two daughters would help put the younger boys to bed. Goals would include a fair and predictable sharing of child care tasks, and Peggy having time after the routine to relax or talk with her daughters. Michael would complete routine tasks more independently and without

behavior problems. Positive patterns of interaction would include the family quieting down and cooperatively preparing for bed, and family members helping each other.

After a vision for each targeted routine was generated, the content and structure of each envisioned routine was discussed with other family members, and family members agreed to support efforts to achieve the vision. The consultant concluded the assessment by explaining how the information gained would drive the design of a behavioral support plan that would fit well with the family's lifestyle, and help them move toward their vision of family life.

Preliminary Plan Design

Based on assessment information the consultant (in continued dialogue with the family) designed a preliminary positive behavioral support plan and an implementation plan that described how interventions would be put into place. The consultant used the plan design guidelines described by Horner, et al. (1993) to select behavioral interventions, and used the guidelines described by Albin, et al. (in press) to ensure that interventions fit well with the characteristics and ecology of the family. Following is an abridged description of this process.

Positive Behavioral Support Plan Design. For each function of the child's behavior problems, ecological, antecedent, skill building, and consequent interventions were proposed that would make behavior problems irrelevant, ineffective, or inefficient for achieving their purposes. For example, Michael often engaged in behavior problems to obtain a preferred item or activity. Proposed interventions logically related to this hypothesis included: (1) making Michael's life more predictable by giving him information about when he can get preferred items and about when he can do preferred activities; (2) giving Michael a personal written schedule to use that

listed his responsibilities and rewards for completing them; (3) teaching Michael verbal negotiation skills including how to make reasonable requests, compromise, and accept limits; (4) using effective positive contingency contracts and praising attempts to use negotiation skills; (5) de-escalating behavior problems at an early stage (e.g., when he whined rather than when he aggressed); and (6) firmly telling him, after he aggresses, that he cannot get what he wants by using this behavior, and making sure that he does not get the desired item or activity for the rest of the day.

Goodness-of-fit was established by first ensuring that interventions advanced family goals, incorporated family knowledge and strengths, used resources available to the family, and appeared likely to diminish stressors. Peggy's goals included Michael becoming more independent during family routines, and herself getting more free time away from child care duties. To accommodate the child-centered goal, a personal schedule was proposed to help Michael self-manage his own bedtime routine. To accommodate the family-centered goal, the weekly use of skilled respite care was proposed so that Peggy could relax and pursue other interests on a regular basis.

Strengths of the family included the family's devotion to the Bible as a source of inspiration and wisdom, and the father's knowledge of several positive strategies for supporting Michael's participation in game activities, chores, and community outings. With the family's Christian values in mind, the consultant asked the family to identify quotes from the Bible that appeared consistent with the emerging support plan, and to use these quotes to fortify and inspire them in their effort to promote change. One quote Peggy found helpful was, "kind words are honey to

the soul and strength to the bones." When Peggy praised Michael's independent performance, she perceived her actions as not only technically correct but also inherently meaningful. The consultant also reflected on the father's use of effective precorrections during difficult tasks, and his use of calm reassurance, explanation, and redirection when Michael began to whine or grow agitated. These parenting skills became important features of teaching strategies and de-escalation procedures in the support plan.

Implementation Support Plan Design. Based on assessment information and discussions with Michael's parents and teacher, a preliminary implementation plan was designed that emphasized direct training support in the home, weekly phone consultation, family team meetings to discuss and role-play interventions and solve new problems, and continued counseling support. The family decided to first implement interventions in the bedtime routine, and then work on improving the leisure, homework, and dinner routines.

Team Meetings and Plan Finalization

Two team meetings were convened to review assessment information and finalize the preliminary positive behavioral support and implementation plans. The meetings were completed in 3½ hours. Meeting participants included Peggy and Alan, Michael's older sisters, his elementary school teacher, a middle school teacher who might assist with his transition to middle school, a TBI consultant to the family, and the family consultants. Michael did not attend the meeting because his family judged that his behavior would be disruptive and make meeting tasks difficult to complete.

The consultant summarized assessment and plan information on flip charts. Meeting participants first reviewed the functional assessment information and the hypotheses about behavior problems. After achieving a consensus on the reasons for Michael's behavior problems the team reviewed and discussed the interventions in the proposed behavior support plan and the support activities and roles described in the proposed implementation plan.

During the reviews and discussions the consultant answered team members' questions and concerns, encouraged suggestions for modifications, and acknowledged team members' contributions. Michael's parents and other team members agreed with the hypotheses about behavior problems and with most of the recommended interventions and support activities, and suggested some improvements. Michael's elementary school teacher also recommended that behavioral consultation meetings be held with middle school teachers and administrators before the start of the next school year to ensure a smooth transition. With team member recommendations incorporated, the plans were finalized. Soon after the meeting, the consultant wrote up the finalized plans and distributed them to team members. Summaries of the positive behavioral support plan and implementation plan are presented in Tables 1 and 2.

Insert Tables 1 and 2 About Here

Implementation Support

During implementation, the consultant helped the family put the plan into place. Over a period of 3 months, the consultant and the family first intervened in the bedroom routine, and

then initiated intervention in the leisure routine. Coaching in home routines and phone consultation typically occurred once per week. Coaching sessions lasted 1 to 1½ hours, while phone consultations lasted 15 to 30 minutes. Approximately once a month a team meeting was held with family members to discuss progress and role play interventions. Support activities used during implementation support are summarized below.

Embedding interventions in envisioned routines. The first task of implementation support was to identify relevant interventions from the support plan and effectively embed them in the first targeted routine -- going to bed. Toward this end, the consultant designed a brief, routine-specific plan that described interventions in terms of the content and structure of the bedtime routine. For example, one goal was for Michael to go to bed independently. Tasks included putting on his pajamas, completing hygiene tasks, and getting into bed. Behavioral interventions were embedded into the routine by teaching Michael to use a personalized self-management notebook that listed the tasks in the bedtime routine, and the reinforcers (e.g., bedtime story, dictate story for journal) available for going to bed cooperatively. The parents were also encouraged to praise Michael whenever he attempted to complete routine steps independently. To ensure that the routine included more frequent and predictable help from other family members, the family negotiated a weekly schedule of helpers and posted the schedule in the kitchen. To achieve the calmer atmosphere envisioned, Michael and his brothers began to go to bed at the same time (between 8:30 and 9:00 p.m.), and other family members agreed to keep activities in the living room quiet after 8:00 p.m.

Coaching. During the first few coaching sessions in the bedtime routine the consultant and family negotiated a style of coaching that was most comfortable to Michael and his parents. At the start of a session, the consultant asked Michael and his parents for their informed consent, and then met briefly with the parents to talk through the use of interventions. During the first few sessions, the consultant modeled the interventions with Michael while his parents observed. During subsequent sessions, the parents implemented interventions while the consultant observed or waited in another room until the routine was completed. After Michael went to bed, the consultant and parents briefly reviewed the session, emphasizing parent skillfulness and child progress.

Phone Consultation and Use of Implementation Checklist. During phone consultation, the consultant and the parents discussed progress in implementing interventions during the previous few days. An implementation checklist was used to structure the discussion. The checklist evaluated Michael's completion of routine steps, the parent's use of interventions, behavior problems, and the acceptability of the support effort (see Table 3). The parents described their successes, continued problems, and feelings or frustrations related to Michael and the support effort. The consultant commended the parents' achievements, helped solve new or recurring problems, and provided emotional support when a parent expressed grief over the child's accident, or frustration with recurring behaviors.

Insert Table 3 About Here

Family Counseling. During natural opportunities that arose in coaching sessions, phone consultations, and family meetings, the consultants helped family members reframe their views of themselves, each other, and Michael. Peggy was encouraged to see herself as a person who proactively solved problems before they happened rather than worry about problems until they occurred. Through modeling and dialogue, the consultants helped family members see Alan as a competent leader in teaching Michael new ways to behave, rather than as a powerless father. Similarly, the family was encouraged to view Michael not as a damaged person but rather as a young boy striving to overcome obstacles to his development that frustrated and confused him.

Coordination of Lifestyle Goals and Transition to Middle School. Concurrent with direct and indirect support for family routines, the consultants and the family collaborated to implement lifestyle interventions such as increasing Michael's friendships and getting skilled respite care into the home on a regular basis. The consultants, for example, collaborated with Peggy to enroll Michael in a summer church camp for non-disabled children, and provided consultation support to the camp counselors. Michael also became a participant in a project whose goal was to help children with TBI develop friendships. During implementation support the consultant facilitated meetings between Peggy and the director of a respite care program, and participated in discussions about the development of skilled respite care for Michael.

At the start of the new school year, the consultants met with school personnel at the middle school, discussed the family's progress, gave the receiving teacher a copy of the behavioral support plan, and discussed interventions that would be relevant to the school setting. In all conversations with school personnel the consultants emphasized the parents' expertise in

supporting Michael, and encouraged administrators and teachers to view Michael's family as a valuable resource to the school, and as able collaborators in the coordination of support between the home and school.

Termination of Implementation Support and Follow-up

Following 7 weeks of implementation support in the bedtime routine (involving ≈17 hrs of direct and indirect support), and 5 weeks of implementation support for the leisure routine (involving ≈12 hrs of primarily indirect support), the family chose to terminate their participation in implementation activities, except for continued phone consultation on as as-needed basis. Their reasons for terminating most implementation support included improvements in Michael's behavior across all routines, family confidence that they could continue supporting Michael without intensive, direct intervention in the home, and Peggy starting a new job and wanting to simplify her life. The consultants supported the family's decision to terminate implementation support, contacted the family by telephone approximately once a month to assess the maintenance of behavioral improvement in Michael, and completed follow-up measures 2, 3, and 5 months after implementation support ended.

Evaluation Methods

Four methods of evaluation were used: (1) A single-case research design summarized direct observations of behavior problems in four family routines; (2) implementation checklists assessed parent fidelity in use of interventions; (3) a social validity measure evaluated the acceptability of plan goals, procedures, and outcomes; and (4) qualitative interviews provided an

interpretation of the family's subjective experience of the support effort. Evaluation methods are summarized below.

Single-case Research Design. A single baseline, time series research design (Barlow & Hersen, 1984) was employed to assess the correlation between implementation of the behavior support plan, and improvement in child behavior in the dinner, homework, leisure, and bedtime routines. The quasi-experimental design had three phases; baseline, intervention, and follow-up. Direct observation of child behavior across the 4 routines was completed by trained observers during each observation session. Three behaviors were operationally defined: (1) aggression, including hitting, kicking, and biting; (2) destructive behaviors including throwing objects, knocking objects off tables or counters, and breaking objects; and (3) screaming, involving high intensity shrieking or shouting. An interval recording method of observation was used, and observations in each routine lasted for 15 minutes. During an observation session, the observer used a clipboard with an earphone attached that emitted a beep every 30 seconds. Following each interval, the observer recorded whether or not behavior problems occurred during the interval.

Observers participated in 10 hours of training including discussion of definitions and procedures, and pilot observations in targeted routines until interobserver agreement scores of 85% or better were achieved. Interobserver agreement was measured in 6 of the 17 (35%) observation sessions, and agreement measures were distributed across the 3 phases of the study. Average interobserver agreement for behavior problems was 88% (range, 79%-99%).

Implementation Fidelity. During phone consultations about intervention in the bedtime routine, the consultant used an implementation checklist to guide an interview with Michael's parents about use of interventions. The family evaluated fidelity using a 5-point Likert scale (1 = not able to use, 5 = used very well). Michael's parents completed this interview on four occasions.

Social Validity. The social validity of the support effort was evaluated during intervention in the bedtime routine and after follow-up measurement. During the parents self-evaluation of the bedtime routine, they also rated statements about the acceptability of the routine (e.g., family members helped, all children went to bed happy) using a 5-point Likert scale (see Table 3). Two months after the last follow-up observation, Michael's mother evaluated the social validity of the overall support effort using a 10 item questionnaire with a 6-point Likert scale (1 = disagree, 6 = agree). The items addressed issues related to the acceptability of support plans goals, procedures, and outcomes.

Qualitative Interviews. Once during implementation support and once again during follow-up, Michael's parents were interviewed about their perceptions of the support effort. The consultant asked 3 open-ended questions: (1) How has Michael's behavior and lifestyle improved since the support effort began, if at all; (2) how has the family's lifestyle improved since the support effort began, if at all; and (3) what problems continue to occur? The first interview was for 45 min, and the second interview lasted 1 hour. The interviews were tape recorded and transcribed. These data then were analyzed for descriptive themes using qualitative

methods of analysis (Gil gun, Daly, & Handel, 1992). Themes that emerged from the data were summarized into a brief interpretation of the family's experience.

Results

Behavior Problems. Data collected across the four routines were combined into a composite percentage of intervals of behavior problems. The composite percentage of intervals with behavior problems across the 4 family routines is presented in Figure 1. Overall, the data indicate significant improvement in the level, trend, and stability of behavior problems across the 4 targeted routines after the positive behavioral support plan was implemented in the bedtime routine, and subsequently (albeit briefly) in the leisure routine. Baseline data show high variability, an increasing trend (split middle method of trend analysis [Tawney & Gast, 1984]), and an average percentage of 10.6 of total intervals evidencing behavior problems. During implementation support, behavior problems fell to a stable average of 1.5% of total intervals observed, and evidenced further improvement (0.5%) 2 and 3 months after implementation support was concluded. Because the data represent a composite percentage across 4 routines, an interpretation of behavior change in any one routine cannot be made. Also, because of limitations inherent in the research design, these changes suggest only a correlation between implementation of the positive behavioral support plan and improvements in child behavior across the 4 routines. A casual relationship cannot be inferred.

Insert Figure 1 about here

Implementation Fidelity. Across 4 ratings (1 = unable to do; 5 = did very well) during implementation support in the bedtime routine, the parents evaluated themselves as increasingly able to implement interventions. During the first self-evaluation the average rating was 3.3, but improved to 4.2 by the last evaluation. These data suggest that the parents perceived themselves as becoming more capable of using interventions effectively in the bedtime routine.

Social Validity. Across 4 ratings (1 = disagree; 5 = agree) of the bedtime routine, Michael's parents indicated that: (1) the routine was not so stressful (2.6); (2) interventions were not difficult to implement (1.5); (3) children went to bed fairly happy (3.8); and (4) they had time to relax (4.2). The parent's evaluation of the comprehensive support effort is presented in Tables 4 and 5. These data suggest that, overall, the family was very satisfied with support goals, interventions, and outcomes.

Insert Tables 4 and 5 here

The Parents' Experience: "He Fits into the Family Better." The qualitative findings served to confirm and further illuminate improvements in Michael's behavior, parent use of behavioral interventions, and overall improvements in the family's lifestyle. The findings also revealed areas where little progress was made and where family problems remained.

Michael's parents consistently reported that Michael was calmer, more cooperative, and more independent in many areas of his life than he had been before the support effort. His parents experienced him as less "whiny" and less apt to escalate into aggressive behaviors. They

estimated that major behavioral incidents had decreased from about once a week to once or twice a month, and that behaviors during an incident were less intense.

Michael's parents partly attributed his gains in independence to changes they had made in themselves. They saw themselves as more patient with him, not expecting him to complete tasks as quickly as he did before the accident. They also noted that they were giving Michael more opportunities to do things for himself. For Michael's part, they perceived a renewed willingness and ability to do things independently. Peggy explained what she meant by independence:

> It means he doesn't need our help as much. He's able to know what he has to do and do it while I can help other members of the family. It means he can take care of himself as far as getting dressed. He's not as demanding or whiny. I don't have to drive him to do things like .. get ready for bed. He's just more confident about the fact that he can do things and that he's part of the family.

His parents also experienced Michael as more willing and able to negotiate wants and to accept compromises or limits. He was viewed as listening more, reasoning better, and trying to understand why he wasn't allowed to do certain things.

Both parents reported that Michael was doing well in middle school, liked his middle school teacher, and had begun to make friends at school. They viewed his teacher as very dedicated and skilled. Although Michael was perceived as having friends at school, his parents reported that he still did not have "after school" friends. A remaining source of frustration and anger for Michael was seeing his younger brother having friends over or leaving the house to visit friends.

Michael's parents viewed themselves as much more effective at parenting Michael. They found themselves using praise, positive contingencies, and precorrections to build cooperation and independence. Peggy described how she often praised him for doing things independently

around the house: "I'll say, `it really helps me when you have the table all set -- all I have to do is get the milk'." His parents also said they were better at de-escalating problems by remaining calm themselves, by not worrying so much about Michael "losing it," and by providing information, reassurance, or redirection before he escalated. Finally, his parents observed that they had become consistent about not giving into Michael when he tried to use behavior problems to enforce his will.

Alan and Peggy described a few improvements in the quality of the family's life together since the start of the support effort. They believed that their relationship had improved, and that they were more supportive of each other. Peggy said she was able to get more rest because Michael's behavior was more predictable, and he was more able to manage his free time. Alan said he was able to take Michael on outings with the other boys successfully because he always told Michael what to expect, and made sure he rewarded the boys for cooperating together. Unsolved problems in the family included Michael's relationship with his 8 year old brother, which remained competitive and contentious, and the continued isolation of the two older daughters from Michael and the rest of the family.

Conclusion

This chapter describes a comprehensive approach to intervention with families of children with TBI and behavior problems that combines current best practice in positive behavioral support, family support, and behavioral parent training. Implementation of the approach was associated with clinically significant improvements in child behavior that maintained during follow-up measures three and four months post intervention.

Four contributions of the family support approach to the TBI rehabilitation field bear emphasis. First, the approach synthesizes a behavior analytic understanding of child behavior problems with an ethnographic view of family ecology and culture. This synthesis contributes to the design of multicomponent positive behavior support plans that are both effective and contextually appropriate for children with TBI and their families.

Second, functional assessment with children experiencing TBI, while acknowledging the influence of trauma on the development of behavior problems, suggests that additional factors influence the development and maintenance of problem behaviors (O'Neill et al., 1990; Wacker et al., in press). These factors include the child's skill deficits, changes in parent-child interaction patterns such that behavior problems are inadvertently strengthened, and decreases in the child's quality of life. The benefit of this expanded view of factors related to problem behaviors is that each skill deficit, detrimental social interaction pattern, or lifestyle loss can be linked to an intervention that may reduce problem behaviors and rebuild adaptive behavior. Families of children with TBI can take heart in a functional perspective on problem behaviors (Carr, Robinson, & Wray Palumbo, 1990). Through this perspective parents may see that (1) their child's behavior problems often serve a clear purpose (i.e., escape demand, get help), (2) problem behaviors are typically triggered by observable events in the environment, and (3) the trauma to the child need not be a solid barrier to behavioral rehabilitation. Empowered by this perspective, families can collaborate with interventionists to design acceptable and effective interventions that address each purpose of the child's problem behaviors.

Third, the collaborative approach to assessment of family ecology naturally encourages professionals to listen to families because this is the only efficient way to gain an in-depth understanding of family characteristics (e.g., goals, strengths, stressors) and family routines (Gallimore, Weisner et al., 1993; Summers et al., 1989). Thus the assessment process inherently honors the family. Several benefits accrue from an assessment approach that may be experienced by families as empowering (Turnbull & Turnbull, 1991c). The development of a therapeutic alliance may be facilitated. A dialogue about family strengths may rekindle the family's sense of hope and self-confidence. An understanding of family routines may lay the groundwork for the design of behavioral interventions that are specially tailored to fit well with the features of the routines.

A final contribution is viewing the family routine as the unit of analysis and intervention (O'Donnell & Tharp, 1990). Because family routines include many of the relevant features of the child's problem behaviors and the family's ecology, intervening within a routine can be a highly efficient and effective means for promoting initial change that the family can see, understand, and attribute to their own effort. For example, when Michael's family successfully intervened in the bedtime routine, they not only improved their son's problem behaviors and their parenting practices; they also improved several other relevant features of family ecology (e.g., equity between mother and father, mother's need for free time, Michael's status vis a vis younger brothers). Equally importantly, the focus and continuity that intervention in one routine provided, allowed Michael's parents to recognize their new found ability to transform a failed routine into a successful one.

Research design and outcome limitations suggest the need for caution when interpreting results. The case study design does not permit certainty about attributing behavioral improvement to the support process. Other factors occuring at the same time as the intervention may also account for improvements in Michael's behavior. Also, although 3 and 4 month follow-up data are encouraging, these data are not sufficient to comment on the long term durability of the support effort. A technology of positive behavioral support and the design of contextually appropriate support plans should promote meaningful change that endures for many years.

A related caution is that the positive behavior support approach did not "cure" Michael of problem behaviors. His continued success at home will depend on the extent tc which family members continue to support him effectively. Because threats to maintenance are numerous in family settings (e.g., fatigue, illness, marital distress; Griest & Forehand, 1982) interventionists will do well to consider ways to support the long term maintenance of positive outcomes. One approach that may have promise is to build periodic follow-up support into a long-term model of support to families (e.g., once every 6 months for 3-5 years).

Future research should replicate the support approach with other families of children with TBI to better demonstrate the efficacy of the approach, and to demonstrate its utility across a diversity of families. Such research should include long-term follow-up measures to better evaluate the durability of multicomponent interventions.

In conclusion, the results, although requiring some caution in their interpretation, nevertheless suggest the promise of the comprehensive family support approach for ameliorating behavior problems in children with TBI, for helping families reintegrate their child with TBI into

valued family routines, and for rebuilding the stability and cohesion that typically characterizes families before the trauma to the child and family.

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Table 1

Multicomponent Positive Behavioral Support Plan

Family-Centered Interventions

1. Plan for skilled respite care at least once a week.
2. Share child care and housecleaning tasks fairly and predictably so that each family member can rest.

Child-Centered Interventions

Lifestyle/Ecological

1. Help Michael feel important (e.g., offer choices and honor reasonable preferences; patiently listen to him; let him do things on his own without unwanted assistance)
2. Support Michael in the development of friendships with non-disabled peers.
3. During major transitions (e.g., back to school after a holiday) increase choice and reinforcement.

Antecedent/Proactive

1. Have Michael use a self-management schedule that reminds him of tasks, social rules, and available reinforcers during routines at home and during classes at school.
2. Provide precorrections before he makes social errors or acts impulsively in the community
3. Support Michael when he does homework by helping him in a quiet room, by interspersing easy/fun tasks with new/difficult tasks, and by using humor to keep the atmosphere lighthearted.

Teaching New Behaviors/Skills

1. Teach Michael to self-manage his schedule of tasks and activities.
2. Teach Michael to negotiate choices and accept compromises and limits.
3. Teach Michael to control his anger by teaching him to say "No big deal" when he makes a mistake, to do deep breathing if he feels upset, and to find an adult to talk to about the problem.

Positive Reinforcement

1. Praise Michael often for trying, independence, and showing self-restraint
2. Use effective positive contingency contracts, and follow through consistently.

De-escalation Strategies.

1. Before Michael escalates: (a) assess the reason for his agitation and use a support strategy that matches the reason; (b) remind him to use his skills instead of his behaviors; (c) prompt or model the use of the appropriate skills; (d) praise remaining calm and trying to use skills; (d) redirect him back to task or activity; and (e) praise re-initiating task or activity.

Negative Consequences.

1. If Michael escalates to get an item or activity: (a) calmly but firmly say, "No"; (b) redirect him to a dissimilar task or activity; (c) remain calm, firm, but sympathetic; and (d) do not negotiate.

2. If Michael escalates to get attention: (a) Calmly but firmly say, "No."; (b) walk away for one to two minutes; (c) return and remind him of rule; (d) tell him when you can give him attention; and (e) redirect him to an activity he can do independently.

Table 2

Implementation Plan

Support Activities (5 month timeline)

1. Written positive behavioral support plan
2. Routine specific plan with implementation checklist
3. Coaching in targeted routines, one at a time (1×/week)
4. Phone consultation (1x/week)
5. Family team meeting to discuss and role play interventions (1x/4-6 wks)
6. Counseling support
7. Friendship development support
8. Transition support to middle school

Roles and Responsibilities

1. Parents: Primary implementors of interventions.
2. Daughters: Informed participants; secondary implementors.
3. Behavior consultant: Primary implementation support person; respite care support and development; support for transition to middle school.
4. Family counselor: Supervisor of clinical support effort; support for lifestyle changes; counseling support.
5. School teachers: Support for transition to middle school; implementation and adaptation of interventions in the school.
6. TBI consultant: Life-planning support; long term social support.

Table 3

Implementation Checklist for Bedtime Routine

Six Steps to a Harmonious Bedtime Routine	Unable to do this / Did this very well
1. Reviewed schedule and rules with Michael.	1 2 3 4 5
2. Offered choice of reward for independence and cooperation.	1 2 3 4 5
3. Only provided help if needed.	1 2 3 4 5
4. Praised independence and following social rules.	1 2 3 4 5
5. If Michael calmly went to bed, I fulfilled the deal.	1 2 3 4 5 NA
6. If Michael hit, kicked or threw things, I did not fulfill the deal.	1 2 3 4 5 NA
How Michael did during routine	**Much help / By self**
1. Completed the routine with little.	1 2 3 4 5
2. Calmly said goodnight and prepared to sleep.	1 2 3 4 5
3. Whined/screamed (# of times).	0 1 2-5 6-10 10 or more
4. Hit, kicked, threw something (# of times).	0 1 2-5 6-10 10 or more
How I feel about the bedtime routine	**Disagree / Agree**
1. The routine was stressful.	1 2 3 4 5
2. The steps to success were difficult to implement.	1 2 3 4 5
3. All children went to bed happy.	1 2 3 4 5
4. I got some relaxation time.	1 2 3 4 5

Table 4

Social Validity Evaluation: Ratings (1 = Disagree; 6 = Agree)

1.	Goals were appropriate	6
2.	Goals were consistent with my family's values	6
3.	Interventions were difficult to carry out	3
4.	Interventions were effective in improving child's behavior	6
5.	Outcomes were beneficial to my child	6
6.	Outcomes were beneficial to my family as a whole	4
7.	The plan caused unanticipated problems in my family.	1
8.	Training activities were well organized and helpful	6
9.	The consultants showed respect for our values	6
10.	Overall, the support effort strengthened my family	6

Table 5

Social Validity Evaluation: Parent Comments

1. We have been successfully taught how to look for and recognize the signs of potential problems that could escalate into inappropriate behavior in our child and how to redirect him in a more positive manner.

2. We are sometimes lulled into forgetting the strategies because Michael behaves so well for longer periods of time and when he or we have a bad day, it takes some quick thinking and attitude adjustments on both parts.

3. Michael is much more cooperative, independent, calm, and pleasant to have around.

4. Living with the pressures and demands of a head injured child along with 4 other siblings will always be stressful but this support has been essential in helping us as parents cope and alleviate a major part of that stress.

Figure Captions

Figure 1. Percentage of intervals with behavior problems during 4 home routines: Dinner, homework, leisure, and going to bed.

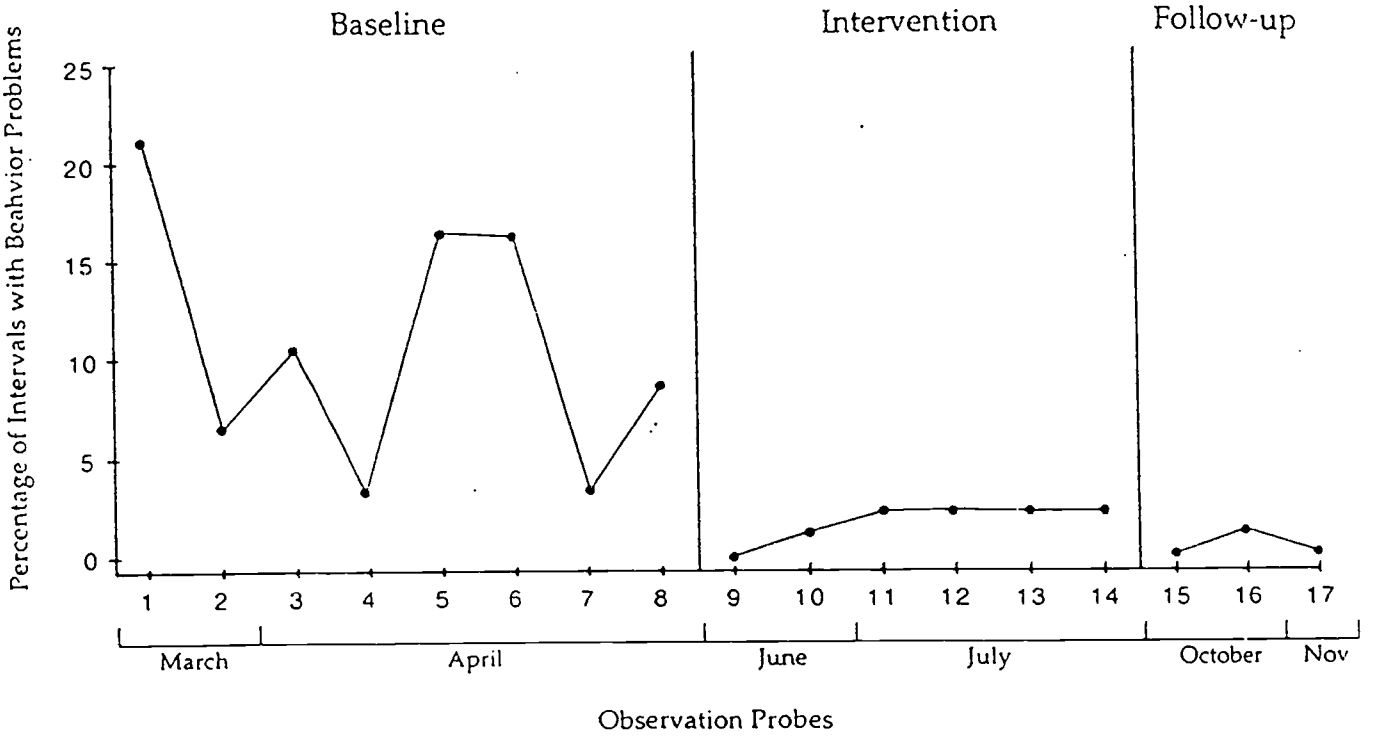

Figure 1. Percentage of intervals with behavior problems during four home routines; dinner, homework, leisure, and going to bed.